Perceived Health Competence, Risk Knowledge, and Self-Management Behaviors in Adolescents and Young Adults with Congenital Heart Disease

Research Thesis

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by

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Abstract

Congenital heart disease (CHD) is the most common birth defect worldwide. As medical professionals continue making improvements to treatment methods, the number of surviving adults afflicted with CHD grows. Individuals with CHD are at elevated risk for multiple comorbidities, including arrhythmias, coronary artery disease, and heart failure. To prevent these health issues, adolescents and young adults with CHD are encouraged by healthcare providers to practice self-management behaviors, such as eating a healthy diet, exercising regularly, and attending follow-up clinic appointments. Self-efficacy and perceived susceptibility, components of the Health Belief Model, have been identified as important constructs for health behavior engagement in other populations. The goal of the current project is to examine the relationship between perceived health competence (PHC; i.e., self-efficacy), risk knowledge (i.e., perceived susceptibility) and self-management behaviors among adolescent and young adult CHD survivors. Participants were recruited from both pediatric and adult outpatient cardiology clinics at Nationwide Children's Hospital and Ohio State University Medical Center (n=239, 15-39 years olds). Self-report measures included (1) the Perceived Health Competence Scale, (2) Risk Knowledge from the CHD Assessment of Information Measure (3) the Fat Intake Scale (diet), (4) and the Godin Leisure-Time Exercise Questionnaire (physical activity). Clinic attendance during a five-year period (2010-2015) was determined from medical charts. Participants were considered "adherent" if they attended >89% of their recommended appointments within a 3-month window. Separate linear regressions were utilized to examine the relationships between perceived health competence, risk knowledge, and self-management behaviors. It was hypothesized that both PHC and risk knowledge would contribute unique variance to self-management behaviors. Results indicated that higher PHC was associated with better clinic

adherence and more physical activity. Furthermore, individuals with greater risk knowledge consumed lower fat diets and engaged in less physical activity. Results from this study may identify potential targets for educational interventions to increase positive self-management behaviors in the CHD community.

Introduction

Congenital heart disease (CHD) is the most common birth defect worldwide (van der Linde et al., 2011). Medical advancements in recent decades have resulted in a dramatic increase in the life expectancies of CHD patients. As medical professionals continue improving treatment methods, the number of surviving adults afflicted with CHD grows (Hoffman, Kaplan, and Libertinson, 2004; Williams et al., 2006). In the United States, CHD affects approximately 1% of births each year (Hoffman and Kaplan 2002; Reller et al., 2008). CHD is the encompassing diagnosis for individuals born with anatomical cardiac defects, known as cardiac lesions. These cardiac lesions can be categorized as "simple", "moderate", or "complex." Due to the varying severities of cardiac lesions, patients require different amounts of care and monitoring throughout their lifetimes. Individuals with "simple" cardiac lesions typically do not require surgical intervention, while "moderate" and "severe" cardiac lesions may require lifelong monitoring and treatment.

Individuals with CHD are at elevated risk for multiple comorbidities, including endocarditis, stroke, aortic aneurysm, coronary artery disease, and congestive heart failure (Oechslin, Harrison, Connelly, Webb, and Siu, 2000; Roche and Silversides, 2013). In addition to these comorbidities, aging adult CHD patients are prone to developing "preventable" diseases seen in aging non-CHD adult populations, such as type 2 diabetes mellitus, myocardial infarction, and obesity (Rosenthal et al., 2016). To prevent these acquired conditions, patients

with CHD are encouraged by healthcare providers to engage in self-management behaviors, including regular exercise, eating an appropriate diet (i.e., low in saturated fat), and presenting to clinic for regular follow-up appointments (Sable et al., 2011). Therefore, better understanding of which factors contribute to proper self-management is important to delineate.

The Health Belief Model has been used to explain health behavior engagement in other disease populations (Rosenstock, 1974). One aspect of the Health Belief Model is perceived susceptibility, or one's perceived risk of a particular negative health outcome if a health behavior is not fulfilled. Perceived susceptibility has been associated with health behaviors in other disease populations, such as better self-management care in a diabetic population, with the management behaviors being measured using the 11 items Toobert & Glasgow scale of diabetes self-care (Dehghani-Tafti et al., 2015). Low perceived susceptibility was found to be associated with low adherence to hypertension medication in a population of rural patients (Kamran et al., 2014). Components of the Health Belief Model, including perceived susceptibility, were found to be positively associated with frequency of the behavior of breast self-examination in a population of metropolitan women (Champion, 1985). However, perceived susceptibility has yet to be examined in the CHD population. Self-efficacy, or perceiving the ability to carry out a health behavior (Bandura, 1986; O'Leary, 1985; Rosenstock, 1974), is another component of the Health Belief Model. A similar construct, perceived health competence (PHC), is the perceived ability to generally manage one's health (Smith, Wallston, and Smith, 1995). Lower PHC has been associated with less physical activity among non-Hodgkin's Lymphoma survivors (Bellizzi et al., 2008). As this measure has been found to be associated with self-management behaviors in other disease populations, it is surprising PHC has yet to be examined among CHD survivors.

Given the importance of proper self-management among CHD survivors, it is remarkable that not more is understood about what factors are associated with better or worse health behavior engagement in this population. Jackson and colleagues (2015) examined the relationship between patient's understanding of future cardiovascular complications due to their CHD diagnosis (risk knowledge) and several health behaviors, including physical activity and diet. Results suggested greater risk knowledge was associated with lower fat intake, and individuals who had higher levels of physical activity reported that they were at risk for less future health complications (Jackson et al., 2015). However, models such as the Health Belief Model stress the importance of not just knowing one's perceived susceptibility, but also perceiving oneself as being able to engage in the behavior. Therefore, the current study aims to determine if risk knowledge and PHC contribute unique variance to self-management behaviors (i.e., clinic adherence, diet, physical activity). It was hypothesized that PHC and risk knowledge would each contribute unique variance to self-management behaviors, such that both risk knowledge and PHC would be positively associated with adherence to clinic appointments, lower saturated fat intake, and higher levels of physical activity. Additionally, it was hypothesized risk knowledge and PHC would be positively associated, such that individuals who possess higher risk knowledge would perceive themselves to be more competent in regards to their health.

Methods

Study Design

The Personal Understanding of my Medical Plan (PUMP) Study was a cross-sectional study, conducted in both pediatric and adult outpatient cardiology clinics at Nationwide Children's Hospital (NCH) and The Ohio State University Medical Center (OSU). Patients were contacted

by phone or in clinic to be recruited after receiving a letter from their cardiologist informing them of the study. Participants were asked to complete online self-report measures of PHC, disease knowledge, saturated fat intake and physical activity at home, on their own without help from others. Medical charts were reviewed to score the disease knowledge measure and obtain information on clinic adherence. Participants received compensation for their time. The study protocol was approved by the IRB at NCH.

Sample

Patients with CHD were recruited from both pediatric and adult outpatient cardiology clinics at NCH and OSU. Eligible patients (1) had a structural heart defect and (2) were between the ages of 15 and 39 years old. Patients were excluded if they (1) were diagnosed with a genetic syndrome that had cardiac involvement (e.g., Down, Marfan, etc.), (2) had a cognitive impairment that would prohibit them from completing the self-report measures, or (3) were not proficient in English.

Measures

Perceived Health Competence

The Perceived Health Competence Scale (PHCS) is an eight-item, self-report measure utilizing a five-point Likert scale ranging from strongly "disagree" to "strongly agree" (1 strongly agree, 2 somewhat agree, 3 neutral, 4 somewhat disagree, 5 strongly disagree). The items consist of general health competence questions (Smith, Wallston, and Smith, 1995). Example items include *"I handle myself well with respect to my health," "No matter how hard I try, my health just doesn't turn out the way I would like,"* and *"It is difficult for me to find effective solutions to the health problems that come my way."* Higher scores suggest higher levels of perceived health competence. Scores range from 8.00-40.00.

Risk knowledge

The CHD Assessment of Information Measure (CHD-AIM), a 24-item self-report measure, was created for the purposes of the PUMP Study and included an assessment of risk knowledge (Jackson et al., 2015). Risk knowledge was assessed by determining participants' ability to identify cardiac-related conditions for which they are at risk due to their cardiac lesion, including arrhythmia, heart failure, stroke, aortic aneurysm, coronary artery disease, and hypertension. These comorbidities require early identification and are major health concerns for varying lesion groups. Additionally, participants were asked to identify symptoms of the conditions they were at risk for, which was scored either as 0, "incorrect," or 1, "correct." Participants were assigned a percentage score (i.e., 0-100%) based on the amount of future health risks and symptoms they identified correctly.

Clinic Adherence

Clinic Adherence was determined from participants' medical records. Recommended clinic appointment dates were identified from healthcare providers' notes, and if participants attended a clinic appointment within a 3-month window of the recommended date, participants were considered "adherent" for that appointment. Participants' appointments were analyzed during a 5-year period (2010-2015), which included 2-years prior to study enrollment and up to 3-years post-enrollment. A total percentage was determined by dividing the number of adherent appointments by the total amount of appointments for the 5-year period. If the resulting percentage was greater than 89%, participants were considered "adherent" (1). If less than 89%, they were marked as "non-adherent" (0).

Diet

The Northwest Lipid Research Clinic Fat Intake Scale (FIS) is a 12-item self-report

questionnaire that asks about the amount of saturated fat consumed within the past month (Retzlaff et al., 1997). The questionnaire gives specific examples of foods containing high levels of saturated fat, including meat, dairy, and snack foods. Scores range from 12.00 to 45.00 with higher scores indicating greater saturated fat intake.

Physical Activity

The Godin Leisure-Time Exercise Questionnaire (GLT) is a two-item self-report measure that provides an estimate of physical activity for a typical week (Godin, Jobin, & Boullion, 1986). Participants identify both the intensity (i.e., mild, moderate, strenuous) and frequency (i.e., number of times per week, lasting 15 minutes or longer). Higher scores suggest greater intensity and frequency of physical activity. Scores range from 0.00-98.00.

Statistical Analyses

A correlation matrix was utilized to examine bivariate associations. Linear regressions examined perceived health competence and risk knowledge as predictors of physical activity and diet. A logistic regression was utilized to examine perceived health competence and risk knowledge as predictors of clinic adherence. Prorating was utilized to calculate estimates of missing items in which less than 20% of the items were missing by averaging the responses for existing items.

Results

Participants included 239 adolescent and young adult survivors of CHD (ages 15-39 years old) representing a variety of lesion severities (simple = 25.4%, moderate = 43.9%, complex = 30.7%). Descriptive statistics for the measures are presented in table 1. The mean for risk knowledge was .53, indicating on average, participants had poor knowledge about future risk and symptoms. Only 36.2% of the sample was considered “adherent” for clinic adherence, and participants reported diets high in saturated fat. Overall self-reported participation in weekly

physical activity was moderate. A correlation matrix revealed PHC was significantly associated with clinic adherence and physical activity. Risk knowledge was significantly associated with diet and physical activity. Risk knowledge and PHC were not associated (Table 2). Age, sex, and race were not significantly associated with the variables.

Results of the linear regressions and logistic regression are represented in Table 3. Greater PHC was associated with being adherent to clinic appointments, but risk knowledge was not predictive of clinic attendance. PHC was positively correlated with clinic adherence, meaning higher PHC scores were correlated with higher levels of attending regular clinic appointments. Risk knowledge was found to be negatively associated with diet, such that participants with higher knowledge of future risk consumed less saturated fat. PHC was not predictive of diet. Both PHC and risk knowledge contributed unique variance to physical activity such that higher levels of PHC was associated with increased physical activity engagement, while higher risk knowledge was associated with lower levels of physical activity.

Discussion

PHC has not been examined as a predictor of self-management behaviors among CHD survivors until now, and little research has been published on the relationship of risk knowledge and self-management behaviors in this population. The utilization of a correlation matrix allowed for the identification of significant bivariate relationships that supported study hypotheses. Risk knowledge was positively associated with better dietary habits (i.e., less saturated fat intake) and PHC was positively associated with clinic adherence and physical activity. Interestingly, the bivariate analysis revealed PHC and risk knowledge were not significantly related. A possible explanation is individuals are over-confident in their abilities to care for themselves, and this

may be completely independent of their actual knowledge of risk. Both PHC and risk knowledge were still hypothesized to be significant contributors of self-management behaviors, regardless of their relationship to one another (Table 2).

PHC and risk knowledge contributed unique variance to the self-management behaviors examined within this study, thereby supporting study hypotheses. As a predictor of physical activity, risk knowledge contradicted study hypotheses. Interestingly, more accurate knowledge of future risk was associated with less physical activity. On average, participants reported optimum levels of physical activity, but this finding has not been consistent across the literature, including in studies that have used an objective measure of physical activity, such as an accelerometer (Dua et al., 2007). As this study's measure of physical activity was self-report, future longitudinal studies should examine this phenomenon using accelerometers within the CHD population. The negative association between future risk knowledge and physical activity can be interpreted several ways. It's plausible individuals who participate in higher levels perceive themselves to be less at risk (Barnhart et al., 2009; Jackson et al., 2015). Individuals who perceive themselves to be at higher risk for complications may be more cautious and avoid physical activity due to concern for fluctuations in somatic sensations (i.e. heartbeat) (Jackson et al., 2015). It's also possible individuals who have higher risk knowledge are not educated in proper physical activity recommendations for CHD survivors, although this explanation is less likely. Future studies should examine this self-management behavior, as physical activity is crucial for maintaining health among CHD survivors (Sable et al., 2011).

Surprisingly, risk knowledge did not contribute significant variance to clinic adherence, and PHC did not contribute to diet. Intuitively, one would predict that greater understanding of one's future risks would inspire adherence to clinic appointments, but this was not the case. It's

plausible other factors contribute more to clinic adherence (i.e., social factors, socioeconomic situation, etc.). Future research should examine contributors to clinic adherence, as monitoring and screening for co-morbidities is critical for the health CHD survivors (Sable et al., 2011).

There were several major study limitations. The study was cross sectional, preventing inferences regarding causality. The relationships presented, however, provide healthcare providers and researchers with valuable insight into possible predictors of self-management behavior. Physical activity and diet were self-report measures, which may be less valid than objective measures of these variables (i.e., blood lipid levels as an indication of diet and accelerometer data for physical activity). The use of objective measures of health behaviors should be considered in future research. Also, PHC and risk knowledge accounted for very little variance in self-management behaviors (Table 3). This finding highlights that many factors likely contribute to self-management behaviors, and the current study only tested a few factors within the Health Belief Model.

As more CHD survivors than ever before enter adulthood, researchers and healthcare providers must find a way to improve self-management behaviors in this population (Hoffman et al., 2004; Williams et al., 2006). Proper monitoring and self-management engagement is crucial for CHD patients (Sable et al., 2011). This study affords healthcare providers and researchers a glance into possible contributors of self-management behavior in CHD survivors. Findings indicate that PHC and risk knowledge are possible contributors to self-management behavior, suggesting educational interventions should be explored as a way to improve both self-efficacy and patient understanding of future health risks. Self-management behavior engagement is critical for CHD patients, and identifying contributors is the first major step in finding ways to

improve these behaviors among this population.

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Table 1. Descriptive statistics.

Variable	Mean (SD) or %	Range
Age	25.76 (7.13)	15-39
Sex (% female)	50.4%	
Race (% white)	88.2%	
PHC	29.25 (6.82)	12.57-40.00
Risk knowledge	0.53(0.29)	0.00-1.00
Clinic adherence (% adherent)	36.2%	
Diet	30.12 (5.37)	13.00-43.00
Physical activity	28.60 (25.37)	0.00-98.00

Table 2. Bivariate Correlation Matrix

	PHC	Risk	Clinic Adherence	Diet	Physical Activity
PHC	-				
Risk	-.084	-			
Clinic Adherence	.147*	-.072	-		
Diet	-.074	-.168*	.113	-	
Physical Activity	.357**	-.273**	-.008	.003	-

($p < .05$) *, ($p < .001$) **

Self-Management Outcome	**B**	**SE (B)**	***B (p)***	**t**	R^2
Clinic Attendance					
PHC	.011	.005	.146 (.025)	2.251	
Risk Knowledge	-.141	.111	-.082 (.206)	-1.268	
					.030
Diet					
PHC	-.071	.051	-.090 (.161)	-1.407	
Risk Knowledge	-3.153	1.201	-.169 (.009)	-2.626	
					.034
Physical Activity					
PHC	1.146	.231	.306 (.000)	4.966	
Risk Knowledge	-21.319	5.441	-.242 (.000)	-3.918	
					.165